

Adult Autism & ADHD Assessment & Diagnostic Service Focus Group

Tuesday 27 April 2021 12-2pm

Staff present	
Sheila Fletcher	Commissioning Specialist, Vale of York CCG
Kate Birkett	Contracting and Commissioning Officer, North Yorkshire CCG
Victoria Binks	Head of Engagement, Vale of York CCG
Bridget Read	Engagement Manager, North Yorkshire CCG
Jane Marchant	Engagement and Administration Officer, North Yorkshire CCG
Members present:	
Angela Fletcher	Happy Futures Support Specialists LTD
Helen Tulloch	Supported Employment NYCC
Helen Scrimshaw	Business Support Officer - Children and Young People
Caroline Shepherdson	Autism Support Group (Malton)
Wendy Collins	Disability Employment Officer, Northallerton & Richmond
Su Dixon	Patient Representative
Victoria Ramskill	Patient Representative
Christopher Dunn	Patient Representative

Sheila Fletcher gave a presentation on the Adult Autism and ADHD Assessment and Diagnostic Service to the group.

The aim of the sessions are to carry out effective engagement on the development of a clear pathway, working in partnership with adults with autism/ADHD and their families/carers.

The present provider for Adult Autism & ADHD Assessment and Diagnostic Service is The Retreat which is based in York. Currently demand is greater than service can allow – current waits 24 months. Waiting lists will be approx. 9 months by April 22.

Additional funding agreed last year, which is non recurrent funding to tackle long waits. We have a high-quality service – the satisfaction and feedback is very good.

There is now a clear commissioning intention for a new service model that would better meet the needs of service users and potentially offer better value for money.

The CCGs will continue the service with the current provider and extend the contract for a further year to 2022. The procurement of a lead provider to deliver an adult

autism and ADHD assessment and diagnosis is taking place and the new contract of the will start from 1 April 2022.

Please see slides for full information on the presentation.

Comment 1: How long do the pre- diagnostic 1:1 sessions last for

Response: Sheila Fletcher replied that the patient usually has 2/3 sessions and after that would be referred back to the GP again then 5 group sessions offered up to specialist service

Comment 2: There are long waiting times for screening.

Response: Patients are triaged, and the Retreat will write to the patient

Comment 3: Is there specified support while people are waiting?

Response: SF replied - Yes there is clinical support within the specialist service.

Comment 4: Please explain what does 'comorbidities' mean in relation to people with Autism and ADHD.

Response: SF stated that some people who present with Autism/ADHD also have and underlying problem e.g. eating disorders.

Comment 5: One attendee explained that he has been referred for diagnosis by the expert mental health unit at Knaresborough and not a GP. Since the referral, their PG has shown little interest in their autism requirements.

Response: The new service model pre-diagnostic support will be available whilst waiting for appointment at the clinic.

Comment 6: My daughter 'masks' at school and therefore the school can't fill in the forms for her to be referred for help. She is 16 and going to college later this year. The referral is through CAMHS.

Response: SF responded that she would like to have a conversation with Victoria about this situation via email. SF asked BR to send her email address to Victoria Ramskill.

Comment 7: Does mandatory training already exist for staff working in Mental Health Service? The attendee also stated that overall North Yorkshire County Council has been brilliant but found local councils not so helpful.

Another attendee confirmed that there is mandatory training for all staff.

Group Discussion:

Following the PowerPoint slides the session was opened up for group discussion.

The group was asked for any ideas how to reach people whilst waiting for their appointment and feeling unsupported. They would be happy to have telephone conversations or to communicate via zoom etc.

Comment 8: If Patient Participation Groups were more active then it would be an avenue to use to get messages out to patients waiting for their appointment.

Response: Bridget Read replied that all information has been circulated out to GP Practice, stakeholders and via social media as well. But always happy to extend circulation.

Comment 9: They train teachers in schools re MH Issues therefore could one GP within the practice be trained who in turn can then train the staff in the practice.

Comment 10: Parents can ring a telephone help line who could advise of a service where to get help for support.

Comment 11: We should set up community groups and establish something that can run itself.

Response: SF replied that looking at setting up support in the community which would include Autism /ADHD and support for improved well being and post diagnostic support.

Comment 12:

Do schools provide specialist Autism teachers – peer support groups can be very helpful?

Response: There are specialist teachers up in Tees Esk and Wear Valleys. North Yorkshire County Council will send someone to the school within their area.

Comment 13: The assessment for children needs to be kept simple – the attendee has spent over 40 hours just trying to sort out paperwork from meetings for her children in one month.

Comment 14: Sharing of information with other departments within the NYCC was very limited and they don't appear to communicate internally.

Comment 15: One of the attendees stated she belongs to a support group and would like to share BR's details with them. BR confirmed she could.

SF commented that The Retreat have stated using a new assessment tool combined with a holistic approach

Comment 16: S Dixon suggested GP Practices initiate more screening questions for patients if they present with depression.

Response: SF advised that primary care will have mental health practitioners working in practices/

Comment 17: When procuring a new service is it down to the budget or finances that determine which centre will be used.

Response: SF responded that it is about money, not quality. Money is a key factor, it has been under invested to meet demand.

Comment 18: Once you are referred documents you receive can be so contractual and off putting.

Response: K Birkett responded she will speak to the Retreat and see what documents are circulated out.

Comment 19: What area does the service cover?

Response: SF stated the service is to cover York and North Yorkshire, no specific location

Next steps: The procurement will be advertised and will be signed off by North Yorkshire and Vale of York CCGs before the procurement site becomes live on 7 June 2021. Contract will be awarded and the new service commence on 1 April 2022.

SF Thanked everyone for coming and participating in the meeting.

Key themes:

- Needs to be support beyond GP
- More awareness of autism in primary care – train the trainer sessions to cascade information about the condition
- Other conditions can often mask autism – eg depression
- Telephone number for people to call while they are waiting for their diagnosis
- More joined up working
- Supporting people through transition from child to adult services
- Reduce endless form filling
- Set up community groups and establish something that can run itself.
- Support after diagnosis
- Joined up working and sharing of information, so that people don't have to keep telling their story again and again
- Clear accessible documentation that is in the appropriate format